



# MS Research Explained...

- The research from TONiC has provided us with invaluable findings that will contribute to helping improve quality of life for people with MS.
- On the following page is a poster presented by a member of the TONiC Study Group at the Joint ACTRIMS-ECTRIMS meeting (European Committee for treatment and research in Multiple Sclerosis). This is the world's largest conference dedicated to understanding and treating MS.
- Below is a plain language summary of the findings.
- By disseminating our research findings to our participants, we hope to encourage continued interest in the TONiC study, as well as to show what research progress we are making as a result of participants' time and effort in taking part.

## **Development of the Neurological Coping Index for Multiple Sclerosis (NCI-MS)**

*C. A. Young, A. Tennant on behalf of the Trajectories of Outcome in Neurological Conditions Study Group.*

Plain language summary:

- The main aim of this research was to create an MS specific coping questionnaire which would look at how patients with MS use different strategies to cope with their condition. Being able to measure coping is a first step to helping people cope better.
- A Coping Index was developed following interviews from a pilot of 18 patients and then provided to 254 MS patients who completed the TONiC questionnaire.
- The Coping Index helps in examining the coping mechanisms used by people with MS. It is hoped this will facilitate future research into coping.

# Development of the Neurological Coping Index for Multiple Sclerosis (NCI-MS)

Young CA<sup>1,2</sup>, Tennant A<sup>3</sup>, on behalf of the TONiC study group

1 The Walton Centre NHS Foundation Trust, UK; 2 University of Liverpool, UK; 3 Schweizer Paraplegiker-Forschung, Switzerland

## Background

Coping in MS refers to cognitive and behavioural efforts to manage stresses imposed by the illness. Several coping strategies may be utilised, such as Problem-focused, Emotion-focused, and Avoidance. The COPE inventory<sup>1</sup> is a 60 item generic measure of coping, but an MS-specific measure of coping has not been published.

## Methods

Following qualitative interviews with MS patients and item extraction, a draft Coping Index was developed and subject to cognitive debriefing with a pilot group of 18 patients. Following this the draft Coping Index and the COPE were incorporated into a questionnaire booklet, which was given to patients (N=401) during routine clinic appointments across three sites in England (Liverpool, Preston, Salford). The questionnaire booklet contained various measures for the Trajectories of Outcomes in Neurological Conditions (TONiC) research programme.

The questionnaire was returned by 254 patients (63.3% response). Fit to the Rasch model was assessed using the chi-square ( $\chi^2$ ) statistic; item and person fit residual SD <1.4; and requiring both the assumptions of local independence of items and unidimensionality to be upheld. Differential Item Functioning (DIF) was tested for age, gender, marital status, disease duration and type, and EDSS level. Concurrent validity was ascertained against the COPE.

**Table 1**

### Demographic characteristics of the sample (n=254)

Age (mean)	50.4 years (SD 12.1)
Sex	174 (68.6%) female
MS type	Relapsing remitting – 48% Rapidly evolving MS* – 15.5% Secondary progressive – 25.4% Primary progressive – 11.1%
Duration of MS (mean, range)	13.2 years (SD9.6)

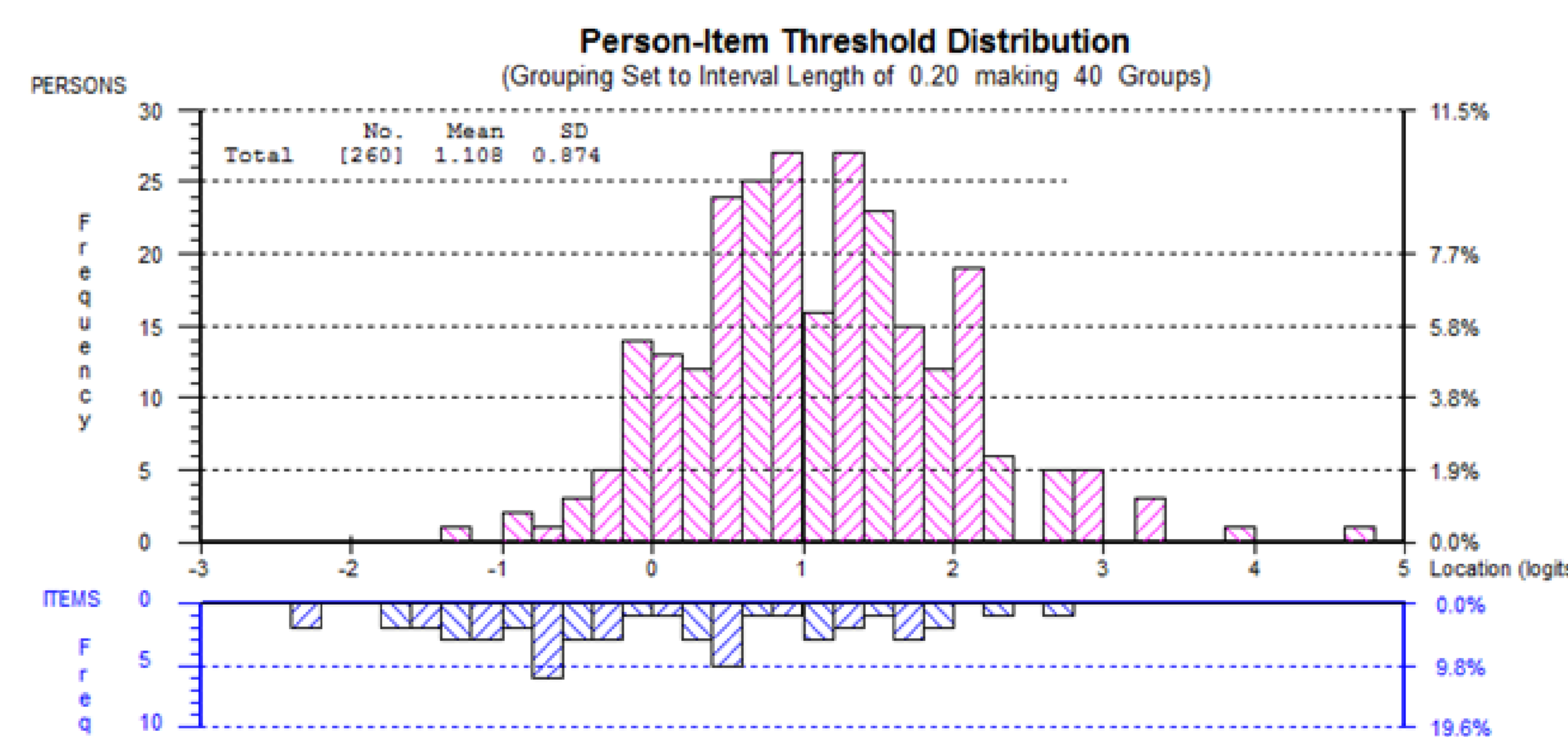
\*Rapidly Evolving MS  
-2 or more disabling relapses in 1 year  
-if MRI has been repeated it should show 1 or more gadolinium enhancing lesions on brain  
-OR a significant increase in T2 lesion load as compared with previous recent MRI

## Results

Data from the 43 draft items were fit to the Rasch model. Initial fit was poor (Chi-Square 649.1;  $p < 0.001$ ) with strong indications of multidimensionality. Consequently two domains were considered, after adjustments for locally dependency and misfit; one 17-item domain associated with a positive 'Approach' such as acceptance and planning, and another of 12 items associated with a negative 'Avoidant' approach such as disengagement and denial. Both had adequate fit to the Rasch model (Approach = Chi-Square 66.3 (df 51);  $p=0.07$ ; mean item fit residual -0.164; SD 1.21; PSI 0.83; Avoidant = Chi-Square 43.0 (df 36);  $p=0.20$ ; mean item fit residual 0.154; SD 0.85; PSI 0.65). Both domains showed positive correlations with their respective comparator domains on the COPE.

A bi-factor solution, based upon both 'Approach' and 'Avoidant' domains, accounted for 83% of the non-error variance.

**Figure 1 – Person and Item Distribution on common metric for coping (approach)**



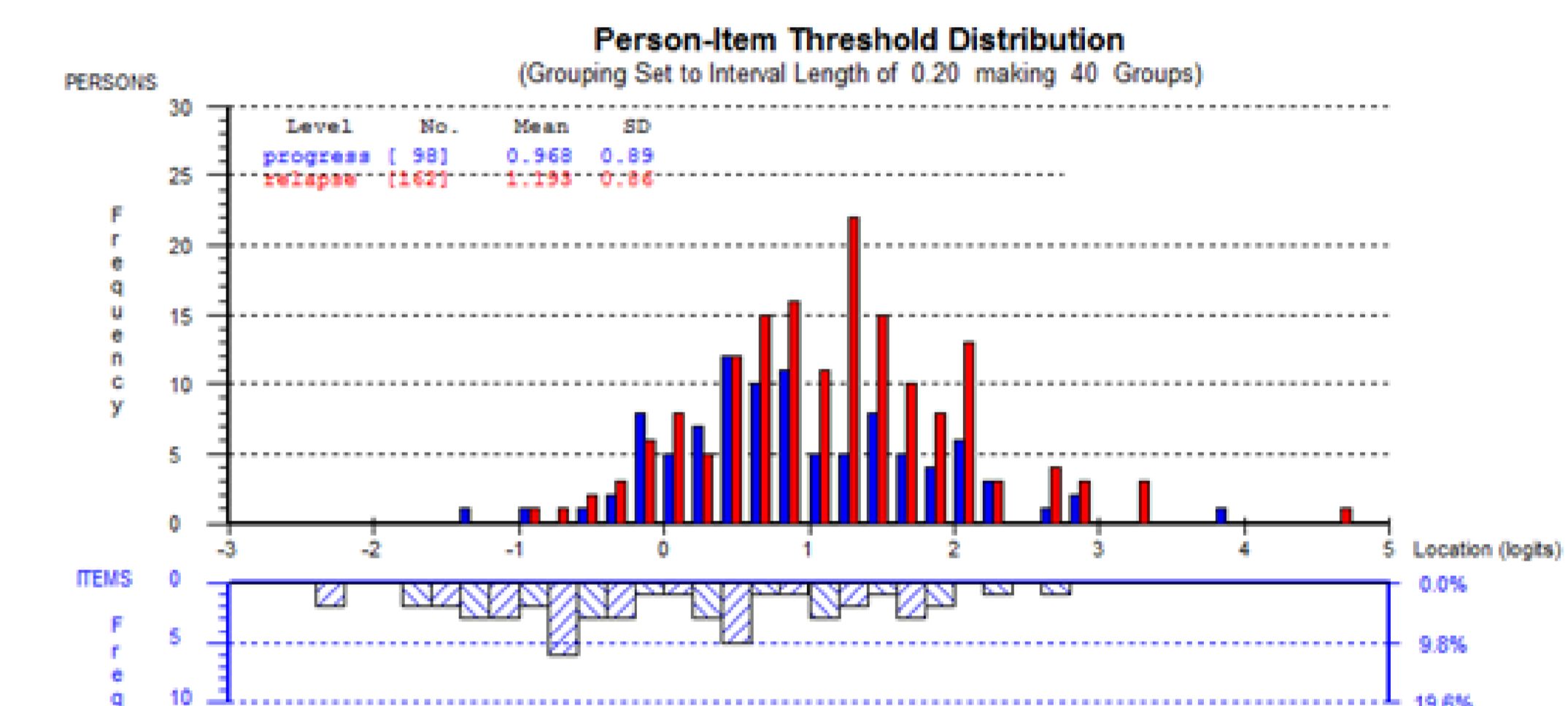
**Table 2 – Most agreed and disagreed items for coping (approach)**

Response	Item
<b>Most readily agreed</b>	I focus on each day as it comes
	I try to lead as normal life as possible
<b>Most readily disagreed</b>	I set myself targets
	I see something good has come from the illness

## Results

Those with a relapsing-remitting type of disease displayed a small but significantly greater level of coping (approach) than those with a progressive form of the disease (t test  $p=0.044$ ).

**Figure 2 – Person and Item Distribution on common metric for coping (approach) by disease type**



## Discussion

A self-completed index of coping for those with MS, consistent with Moos theory of coping<sup>2</sup>, built from the patient experience and satisfying Rasch measurement model standards, will provide a disease-specific scale for this important mediating construct. The TONiC group are currently obtaining data from a second cohort of 260 participants to check that this solution can be replicated.

### References

1. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology* 1989; 56: 267-283.
2. Moos RH, Holahan CJ. Dispositional and contextual perspectives on coping: Toward an integrative framework. *Journal of Clinical Psychology*. 2003;59:1387-1403.

### Acknowledgements

We thank the participants and the TONiC team.

### Disclosures

CAYoung serves on the scientific advisory boards for Biogen Idec, Novartis, and Teva and has received research funding from the MND, CLRN & British Polio Fellowship. A Tennant has no disclosures. TONiC is an investigator-lead, multicentre study covering the UK, which receives unrestricted grants from MND, Biogen, Novartis, Roche and Teva

For more information regarding TONiC, please visit our website ([www.tonicstudy.org](http://www.tonicstudy.org))

